

GUIDE TO SUPPORT PARENT'S

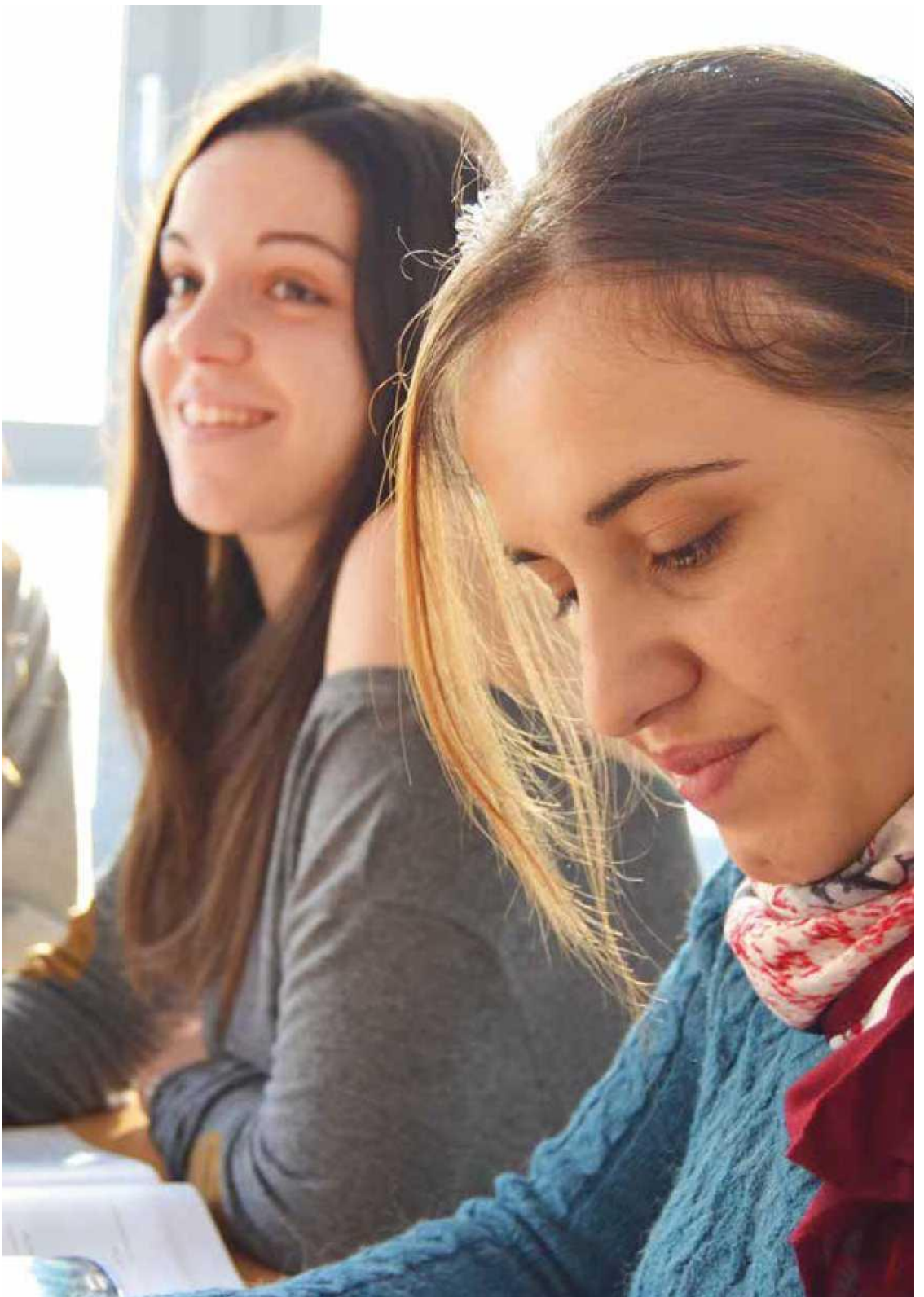


12-17
years

GROWING
A CHILD WITH
A PATHOLOGY
RARE

Adolescence is a moment of transformation, from the immaturity of childhood to adulthood. There are no border lines or specific events representing the end of childhood or the beginning of adolescence. The transition from childhood to adolescence consists of a series of changes that gradually manifest themselves, and touch the behaviour, development and relationships of a young person in many respects.

This guide proposes practical strategies for parents of children born with a rare pathology, to support them during their adolescence years.



UNDERSTANDING ADOLESCENCE

Adolescence is a psychological turning point in a young person's life; the thoughts, ideas and concepts that your children develop during this period will greatly affect their lives, playing a fundamental role in the formation of character and personality. It is also a period of rapid physical, emotional development and remarkable mood swings. These are engaging developments and changes, but they can also generate confusion and difficulty for both your child and you as parents.

Adolescence is one of the fundamental, if not the most important, passages of a person's life and is the most significant at a time when the concept of identity becomes extremely important. For young people this period can be disconcerting and is often accompanied by difficult questions: "Who am I?", "Who do I want to be?", "How do I get there?"

It is also a time when young people begin to investigate, ask questions and raise doubts about everything about their lives and this can sometimes be seen as a challenge. For parents it can be exasperating as they might think that their children are questioning everything just for the sake of discussion.

As they become increasingly independent, young people want to experience new things, often without having enough experience to count on when things become difficult. At the same time, they are extremely attentive to how they are seen by others, especially their peers; this could produce sudden changes in self-esteem and behavior in general, making them feel adults at one time and extra small and inexperienced in the other.

During these years you will need to be flexible in your own parenting style; sometimes you may feel overwhelmed; therefore, it is important to remember that growing up a teenager is only a passing period, it will pass.

Young people want to be recognised for what they are, even if they have no idea who they would like to be. With your support, your patience and understanding, they will meet their growing need to develop an independent identity.

IDENTITY AND APPEARANCE

Adolescence is a period when the interlinkages between appearance and identity become more stringent and evident. The body image and the way you see them is an important concern for girls and boys in this age group, more than at other stages of life.

Worrying about the physical appearance contributes more than any other factor to determining the levels of self-esteem of young people. With puberty, some teenagers have problems with their self-esteem because the body undergoes many changes that, combined with the natural desire to feel accepted, lead many teenagers to confront the people around them, or with the "perfect" and retouched images of actors and celebrities that are bombarded on social media, TV and movies.

To your son it may seem that the world in which he is trying to fit in gives more value to appearance than to the substance. For young people living with a rare pathology, these concerns can be amplified by long-lived beliefs and doubts about their body image.

Most children have a body awareness from an early age, but this usually implies facing growth and maturity; it also increases awareness of the physical difference compared to others. Although the rare pathologist has existed since birth, this growing awareness of diversity can be extremely impacting on the self-esteem levels of a teenager.

Encourage your son to talk about his feelings

If your child is concerned about his appearance, encourage him to talk about his feelings and his sorrows. Create a secure space to express your doubts, your anger and frustration. Make sure he knows that you are listening and recognise all the problems he is trying to face, showing that he sees his growing maturity without minimising or

ignoring his anxieties.

Offer reassurances

Sometimes the need to conform to the “standard” or to be equal to other peers may be oppressive for young people. Sometimes physical changes can take place quite quickly and this could lead your child to need to be reassured, especially if he does not feel up to his peers.

Reassure him by explaining that it is normal to be a little worried or to feel uncomfortable, because even his peers have anxieties and doubts about their appearance. Let them know that everyone is different: there are those who mature early, those who develop later and those who grow slowly but gradually. In other words, different modes of development can be considered normal.

Be positive about your child's appearance

Self-esteem and one's own value are important factors in overcoming negative feelings. Some statements of your children, such as “I am so ugly” or “I hate my appearance”, can be addressed positively and gently by often making various comments about their appearance: “You have beautiful eyes”, “You have a beautiful smile”, “You have really beautiful hair”, “You look really good dressed like this.”

Try to avoid istic paternalstatements like “Don't worry, theimportant is what you have inside.” Many young people with a rare pathology feel degraded by these comments; instead, they must and will want to know that you find them beautiful both inside and outside.

It is also important that your child focuses on the parts of his appearance that make him feel more confident. Young people tend to focus on what they feel negative about their appearance, so help them feel safer by encouraging them to buy new clothes or try a new haircut.

Help your child question what he thinks of his physical appearance

Movies, TV shows, magazines and social media often suggest that, in order to be happy and succeed, we need to appear in a certain way. You can help your children question this conviction byasking why he wants to look like a particular person, such as a Hollywood star.

You will find that often this “beautiful” person represents a dream or a particular lifestyle that your child considers unreachable, saying, for example: Because I want to be an actor. Try to find out more by asking: “Would you like to recite?”, if he said yes, you could ask, for example: “If this is your dream then we don't wait for Hollywood, let's try to commit now. Would you like to try acting classes? In this way you can begin to understand that often dreams can come true “by going and getting” rather than “waiting and hoping”.

Encouraging activities and interests

Young people with a rare disease may doubt whether they can find a place in the world; their goals could be conditioned by thoughts such as: “I can't participate” or “I don't think I can learn to do that.” Face these withnegative winnings or thoughts by supporting the talents, hopes and desires of your children by encouraging them to participate in activities that might interest them. A positive image that includes not only the physical appearance and giant snow but also its talents and the positive traits of its personality will help them to feel more confident and improve self-esteem. Let them never forget everything they know how to do, such as dancing, singing, sports, acting, etc.

HELP YOUR CHILD GAIN INDEPENDENCE

The main goal of adolescence is often to be increasingly independent, to do so the teenagers willbegin to move away from their parents. You may find that your sweet and loving son, who first wanted to please you, will suddenly begin to want to assert himself and rebel strongly against your control.

You may also find that you are considered increasingly embarrassing for your teenage children: now your views, your appearance and your values can be criticised and often rejected because “old style”, out of fashion or too conventional.

Usually these rejections and conflicts have nothing to do with your personality, they simply stem from the fact that you



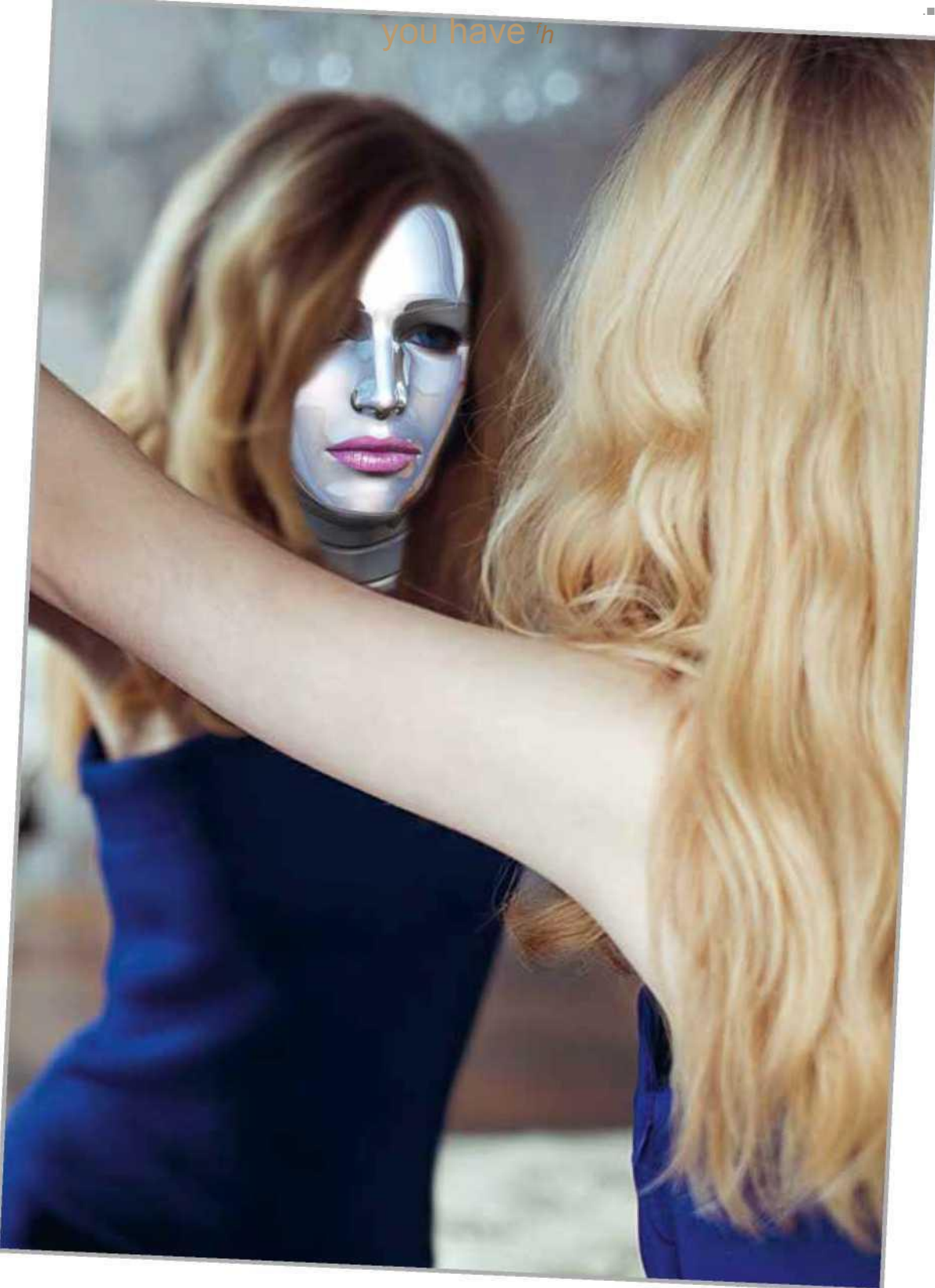
are “the parents”, from which your child wants to become independent if he wants to have his own life. However, it is understandable to feel rejected at this time, so it can help to rethink your teenage years: can you remember the struggles with your appearance? How did you feel? How did you relate to your parents and the world? Are you ready to see these changes even in your child? Are you willing to accept that their opinions and tastes are different from yours? Parents who are aware of any change will be more prepared to deal with it.

Setting limits

Parents and teens often complain about each other’s behavior. Parents repeatedly feel that they have lost all sorts of control or influence over their children, while adolescents need their parents to be clear and consistent about rules and borders, while at the same time being affected by any restrictions on their growing freedom and ability to decide on their own.

However, they need to know, and usually understand, that you are worried enough to expect something from them. School performance, composition and respect for house rules are important standards by

you have 'h



maintain: if you have feasible and appropriate expectations, your children will probably try to satisfy them.

Involve your teenage child in the definition of family rules; as for everyone, it is more likely that they will stick to the rules if they can see their logic and if they have helped to create them. Parents should choose their battles, not all frustrations are worth a discussion; it is usually better to spend time praising the right decisions and their good behavior. Interestingly, most of the most annoying habits run out on their own once parents stop reacting to them.

Let go

Every parent must recognise and be ready to allow their children who have grown up to become independent and self-sufficient. Letting them go can be particularly difficult to do if you have a rare pathology because your fundamental need for independence can be influenced by your own doubts and uncertainties, such as:

- Can I live my life?
- Can I become who I want to be?
- Will I be able to make my decisions?

The subtle balance between being giant incoragand being realistic about their current capabilities is not always easy to establish. Sometimes all we need is continuous encouragement, reassuranceand understanding. The temptation to be overprotective is understandable but helping your child manage himself is the best kind of support and guidance you can give.

TALK TO YOUR TEENAGE SON OF THE NMCG

Young people may often have veryrealistic anxiety, anxiety and fears about their pathology. If you don't talk about it directly, they might start wondering why. Sometimes, young people end up either feeling very lonely and scared to talk about it, or convinced they are different because they

did something wrong. If you talk about his condition with confidence and in a concrete way, you can appease these fears before they arise and this in turn will help them to feel more confident and confident. You will also give your children the words to use to formulate phrases, both to respond to people's curiosity and to express their feelings, thoughts and fears about the pathology. But above all, you will instill the conviction that their diversity is not to be demonised. What will help your teenager to feel more confident, especially in social interactions, will be a positive self-image that will not only understand the NMCG butalso the recognition of their charm, talents and personality traits.

Your children live with giant snow since birth so you may have already established ways to talk about it. The following tips can still help you:

- Use websites to help him better understand the pathology
- Describe how his condition affects him
- Use medical names of the pathology (Nevo melanocytic Congenital Giant)
- Talk about the similarities, as well as the differences, which it has compared to other people.

MANAGE REACTIONS WITH OTHERS

Making new acquaintances in the social context can be unnerving for those who are very young, but for adolescents with a rare pathology it may be more difficult. It is likely that a young person with an aesthetic diversity encounters curiosity in the form of sudden glances or glances, sometimes even expressions of shock. It is important to teach them how to manage the reactions of others in a positive way and develop a safe behavior, especially because it will become more and more independent of you. Being prepared to answer comments, questions or looks helps them feel they have control of the situation.

Prepare your teenage son to know what to say

Make sure your child has clear and correct information about his condition, this will allow him to create phrases to use when people ask for giant snow, such as: I was born with a stain. It's not a big deal, it doesn't hurt.

Encourage them to practice with you at home on what he wants to say and how to say it, until he feels comfortable talking about his pathology in other situations or contexts.

When you feel more comfortable you can also take the initiative instead of waiting for others to say what, for example: I see you've noticed my hands. He's a giant neo, I was born there. It doesn't hurt at all.

Remember to praise your children and show that you recognise their improvements: I really liked the way you handled the situation, good.

Be a reference figure

As a parent, the way you treat and manage the reactions of others, as well as what you say and the way you say it, will be an important example for your children by showing you relaxed, safe and at ease, you will provide a fundamental model that will help them in social interactions

Reassure

Try to reassure your child that one of the main reasons people look at him is to communicate with him; we all look at people's faces both when we speak and when we listen, it is a normal and natural aspect of communication.

If your teenage daughters are aware of their own appearance, this apparent

"examination" by other people can unfortunately be considered uncomfortable and intrusive. It is important to explain that people are curious

by nature and that we all tend to browse and want to know more about something that is new to us. Everyone instinctively looks at faces because faces provide information, they feel the mood, and often the unspoken thoughts of the other person.

Managing maleducation

Some people may be rude if they do not know how to respond appropriately to aesthetic diversity. Show your children how to be determined; being able to assert what they feel and want without getting angry or offending can be a very effective way to deal with rudeness. One could say: "I have the NMCG. It is a rare neo with which I was born. Instead of just looking at it, ask me something to know more".

Remind your children that it is also right

to let go and, if he is at school, to find a teacher to be reassured and supported.

There will be **times when your child won't feel like answering to other people. Make sure he knows he doesn't have to explain himself every time. In these moments what can help is to focus on something positive that you can tell yourself, to deal with the negative thoughts that might appear when you meet new people. By continuing to read this guide, you will find a list of positive phrases that many young people with the NMCG have found reassuring.**

THE SPIEGA-REASSURE-DISTRATE TECHNIQUE



•

The parent support guides explain this technique to help you parents communicate with your children about the giant snow. When they reach adolescence, you may want to explain the technique so that you can use it yourself.

The SPIEGA-RASSICURA TECHNICAL-distract your child:

- Make the first move
- Feel you have more control
- Preserving self-esteem and trust
- Dealing with all kinds of curiosities of others
- Learn how to respond to this curiosity to help develop skills to use with new knowledge;

The general rule is: the more the interaction has an important value to you, the more you will improve the technique.

Scenario 1

It may be suggested to your figlio that, for example, if you are aware that some people have noticed the NMCG while walking or at the bus stop, there is no need to provide a long and in-depth explanation. He can simply smile or say "Hello", to reassure them or stop their gaze. Some people might then ask a few questions, at which point a short and coincident answer is enough. This will allow him to continue to live his day more serenely.

Scenario 2

When your daughter wants to make new friends she may want to talk about the NMCG in detail and not with a quick

comment. Giving more information reassures people, so giving more details about the NMCG — or what it is or the fact that we were born — can be helpful. Your child can then distract their interlocutors by talking about what they share, such as a hobby, or the latest news: everyday things.

Scenario 3

There will be times when your child will want to explain to others what the NMCG is. Suggest using the "Distrarre" technique, asking others questions about them or moving the conversation to another topic.

Scenario 4

Your child knows well in mind that people can make rationale minds about his NMCG that lead to sacrificed questions, explicit or implicit, such as: "Is it contagious?" or "Do you need help?". Although some guys with the NMCG may need extra help, this is not always the case, because thanks to the rule of SPIEGARE- reassure-distrarre you can reassure others and delete any incorrect reasoning. You can talk about your own experience with the NMCG, also and above all about some positive experiences.

THE IMPORTANCE OF FRIENDSHIP

•

Although close relationships with friends exist well before adolescence, during these years relationships change in meaning and structure. There is a true sense of conviviality, a total understanding of the

feelings, hopes and fears of the other. For the first time there is also the feeling of being “we against them” and an acknowledgement of the division between generations. At this point, your son might consider his most important and influential friends in his family.

These relationships are important because they serve to understand how to get along with other people and how to acquire a sense of identity distinct from that of the family. However, fears of being in the “right” group compared to the “wrong” group may lead to new pressures, especially when the desire to belong and to be accepted seems to be of utmost importance.

Young people with a rare pathology have many things in common with their peers, but they can also often feel excluded and insecure, especially if attention is focused only on aesthetics and external appearance.

It is important to encourage your child to engage in the community, to make friends by sharing common interests; support him in engaging in social activities, participating in various associations, such as youth groups, football teams and dance courses. At home, adopt a policy of “open doors” towards friends: the house must represent security, love and affection and must not become a refuge against the world. Rather, the world should be more and more omnipresent and welcoming.

BOYFRIENDS AND GIRLFRIENDS

The confusional state of adolescence becomes even more complicated with the arrival of new emotional feelings towards

peers. The boys and girls who have been judged for so long by your children as annoying elements can suddenly become interesting, for which you create a feeling.

“No one will ever love me” will then be added to the list of concerns of your children.

The way teenagers feel is often determined by how people approach them. For example, if they respond with love, your children will feel loved; if the answer is to exclude, they will not feel desired. Your teenager’s self-esteem will be increasingly determined by the opinions of others.

For young people with a rare pathology there is often both a concern and a

desire to be like their peers. It can be difficult for a parent to listen to phrases such as: “She is beautiful, that’s why she has a boyfriend, it will never happen to me” or “He is tall and cool, that’s why she has a girlfriend, I will never find her” or, above all, “With my snow no one will want me”.

In this period they will be increasingly aware of the attitude that you have as parents, so it is important that you constantly reconfirm an optimistic message being positive, confident and constructive. Remind your child that the reactions of others towards us are strongly influenced by how we present ourselves. Appearing flighty, interesting and handy are key elements for the success of any new relationship.

Parents of teen threads, with a rare

pathology, just like their own filias, often feel a lot of anxiety about what will happen if they have a sentimental relationship. They might worry about how to talk about the giant snow, especially if located in a part of the body that does not make it visible except by undressing. If you think that your child can be tormented by these thoughts, ask gently if he wants to talk about it, reassure him that there are always solutions and that it may only take some practice, attempts and errors before finding what is best for them.

SELF-ENCOURAGEMENT SPEECH

- Give your child, but also to yourself, a bang of confidence with some reassuring phrases to repeat when you are in difficult situations. The acronym of the poster by Caring



Matters Now “SMILE” is a wonderful resource to exhibit at home, a set of positive remarks to memorise:

- S = Spick in the Crowd
- M = draw the maximum from its own uniqueness
- I = Inspire others
- L = Love your skin
- E = Embrace your diversity

BROTHERS AND SISTERS

The fact that your child has a rare pathology somehow affects all members of the family. Most brothers or sisters will do well if they help them understand the aesthetic diversity of their sister's brother, if they manage to share their feelings and concerns.

However, they will be aware of unwanted looks and comments, they may receive questions about the appearance of their brother or sister, so it is important that they are included in the discussions on how to respond to others, so that they too can feel confident when faced with questions or comments.

Rivalry between siblings can be a common factor in the household and during adolescence this can emerge more clearly. As parents it is important to be aware that this rivalry can be triggered by the amount of time you spend to take care of your child with the NMCG.

From medical appointments to being certain of his emotional well-being, parents can feel too absorbed by having to take care of their children with a rare pathology; make sure you have some time alone with your other children, focus on their needs and give them all your attention.

It is also important that close family members have their own place to meet other children's brothers or sisters with the NMCG, share experiences by making friends.

START OF SECONDARY SCHOOL

When your children start secondary school, you may request a meeting with the principal and class representative to share information about the NMCG and how snow affects your children's lives.

You could provide the Naevus Italia association flyer school or offer Formaizone courses and update for teachers that Naevus Italia ODV offers in different cities of Italy.

To request information please contact: segreteria@nevogigante.it or visit <https://www.nevogigante.it/> or the website of the international association: <https://naevusglobal.org/>

CMTC-ovm
Nevus netwerk nederland
naevus global



GROWING A CHILD WITH A PATHOLOGY RARE

naevus italia odv
sponsored by